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Implementing a Population-Based Breast Cancer Risk Assessment Program

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Abstract

Challenges exist in implementing population-based cancer risk assessment programs and making appropriate referrals. We implemented a semiautomated mechanism to assess breast cancer risk and implement counseling. Among 20,558 women, 420 were identified as elevated risk using personal and family risk information with verification by genetic counselors. Population-based breast cancer screening and counseling is feasible but resource-intensive.

Background: Personalized breast cancer risk assessment is important in identifying and managing women at increased risk for breast cancer. However, there has been little evaluation of the practical aspects of implementing a population-based program that identifies and refers high-risk patients for further evaluation. **Patients and Methods:** We implemented a semiautomated approach to collect personal and family history to identify women at high risk of breast cancer. On the basis of the survey, women identified as elevated risk received letters inviting them to telephone consultations with licensed breast health genetic counselors (BHGCs). High-risk women's history was verified and counseling and referrals provided, as appropriate. **Results:** Among 20,558 women screened, 2000 (9.7%) women were identified as high risk on the basis of patient initial report. However, most (1,580) were excluded from receiving risk communication after BHGC review of risk information with the woman or because of previous attention to breast cancer risk or an abnormal mammogram. Among 420 subjects who received risk letters, 225 received a BHGC consultation. Of these 225 women, 63 were reclassified as average risk, 158 were referred to high-risk clinics, and 5 consultations were incomplete after determining that further information was needed. Of the 158 women referred to high-risk breast clinics, 51 attended an appointment. **Conclusion:** This study highlights the complex nature of a population-based breast cancer screening program in a clinical setting and shows the substantial effort needed to identify newly discovered women at high risk for breast cancer and refer them to appropriate services.

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Keywords: Breast cancer screening, Population-based study, Risk assessment, Risk communication, Risk prevention

Introduction

Implementing a personalized breast cancer risk assessment program has the potential benefit of identifying women at high risk of breast cancer.[1] This can facilitate receipt of personalized strategies of breast cancer risk reduction such as chemoprevention,[2-4] mastectomy,[5] or lifestyle modification. The comprehensive risk information also might guide more appropriate risk surveillance test frequency.[6]

To implement a population-based risk assessment program into routine breast cancer screening in busy high-volume breast radiology clinics and primary care provider (PCP) practices, many

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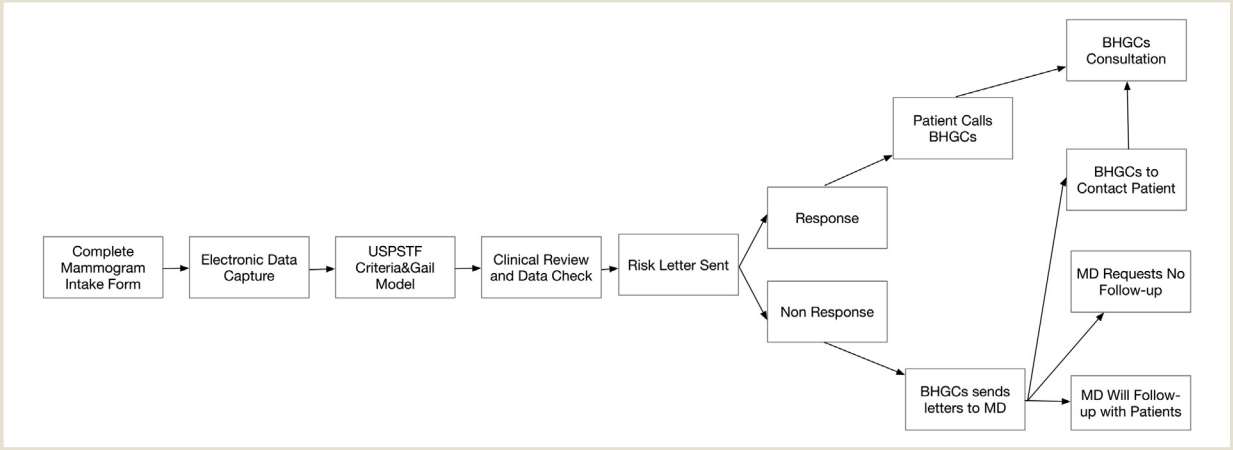
Figure 1 Process to Identify High-Risk Women and Breast Health Genetic Counselors (BHGCs) Intervention



processes must interdigitate and reliable screening mechanisms are needed.[7-10] The goal is to ensure that women newly identified at elevated risk of breast cancer are referred in a timely manner to appropriate genetic counseling, genetic testing, and risk prevention services, while minimizing the anxiety of patients and the uncertainty of referring physicians.[10-12] For this to be successful, models must exist to translate women's personal and family history into predictions of breast cancer risk.

Although many models, such as that of Gail et al (Gail model),[13] International Breast Intervention Study,[14] The Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm,[15] Claus et al,[16] BRCAPRO genetic risk prediction model,[17] and Jonker et al[18] are used to predict breast cancer risk, no consistent model has been used for screening in large populations because of limited discriminatory accuracy.[19-21] Among all of the models, the Gail model is most commonly used for breast cancer risk assessment and it has been validated in 3 large populations.[22] However, studies have shown that the Gail model underestimates the risk of breast cancer, and particularly that it underestimates the risk of women who have a family history of breast cancer in non–first-degree relatives or have a family history of other hereditary breast and ovarian cancers.[19,20]

The University of California, Los Angeles (UCLA) Health System, as part of a University of California-wide quality improvement initiative (Athena Breast Health Network[23]), initiated an ongoing population-based breast cancer risk assessment program in 2011. Athena integrated the Gail model and US Preventive Service Task Force (USPSTF) guidelines[24] into an Athena Breast Health Questionnaire (ABHQ, see Supplemental Figure 1 in the online version) to collect self-reported personal and family history. Women answered the ABHQ at the time of mammography screening, which was chosen because women are activated to participate in a personalized risk assessment and they will have an available mammogram to contribute to the risk assessment.

A novel aspect of this program is that breast health genetic counselors (BHGCs), licensed genetic counselors trained in breast cancer risk assessment, review patient-reported and electronic medical record (EMR) data, coordinate notifications of risk assessment results, and provide telephone-based consultations to women at elevated risk of breast cancer. After assessment and counseling, the BHGC refers high-risk women to the breast cancer high-risk clinic. Inclusion of BHGCs in the program permitted verification of patient self-reported data, delivery of risk communication while minimizing anxiety, and ensured that referrals are made on the basis of patient need.

In this article, we describe a population-based breast cancer screening program. We describe the process of using patient self-report to evaluate a patient's breast cancer risk using the Gail model and USPSTF guidelines and identify the challenges of implementing a population-based personalized breast cancer risk assessment program.

Patients and Methods

Athena High Risk Assessment Program

The Athena program at UCLA performed risk assessment and risk communication for women receiving mammography or ultrasound examination at 3 UCLA breast imaging centers. The program was conducted as a multisite quality improvement project without requirement for written informed consent. Women identified as high breast cancer risk received letters informing them of risk status and inviting them to consult with the BHGC (Figure 1). This quality improvement project received UCLA institutional review board approval (N10-001083).

Patients and Data Collection

All women who presented for a screening mammogram were asked by the radiology department to complete the ABHQ. This survey asked subjects about personal and family history and their willingness to be contacted for future research. The ABHQ was completed in the waiting room. Subjects could choose either a paper- or a tablet-based ABHQ.

Trigger Validation

A validation process was conducted on the ABHQ before the study was fully launched with the intent to remove from the survey high-risk breast cancer triggers that performed with low accuracy

Table 1 Characteristics of Women at Various Stages of a Population-Based Breast Cancer Risk Screening Program[a]

	2000 Were Identified as High Risk	420 Were Sent a Risk Letter	135 Contacted a BHGC	285 Did Not Contact a BHGC	225 Consultation Completed
Age Group					
<29	36 (2)	7 (2)	6 (4)	6 (2)	2 (1)
30-39	114 (6)	25 (6)	42 (31)	19 (7)	11 (5)
40-49	486 (24)	127 (30)	42 (31)	86 (30)	70 (31)
50-59	562 (28)	151 (36)	42 (32)	111 (39)	70 (31)
60-69	492 (25)	107 (26)	2 (1)	63 (22)	72 (31)
>70	310 (16)	0 (0)	0 (0)	0 (0)	0 (0)
Race/Ethnicity					
White	1422 (71)	259 (62)	89 (66)	170 (60)	143 (63)
Black	98 (5)	31 (7)	9 (7)	22 (7)	17 (8)
Asian	205 (10)	56 (13)	20 (15)	36 (13)	31 (14)
Other	275 (14)	74 (18)	17 (13)	57 (20)	34 (15)
Hispanic	196 (10)	52 (12)	11 (8)	41 (14)	25 (11)
Education					
Post graduate/college	1400 (70)	322 (77)	108 (80)	214 (75)	178 (79)
Some college	358 (18)	65 (15)	18 (13)	48 (17)	34 (15)
High school graduate	106 (5)	17 (4)	4 (3)	14 (5)	4 (2)
Some high school	32 (2)	5 (1)	2 (1)	3 (1)	4 (2)
Others	104 (5)	11 (3)	3 (3)	6 (2)	5 (2)

Data are presented as n (%). See Figure 1 for flow of breast cancer risk screening program.
Abbreviation: BHGC = breast health genetic counselor.
[a]Comparison of women's sociodemographic data among 2000 women who initially screened as high risk for breast cancer, 420 women who received risk a letter, 135 women who contacted a BHGC, 285 women did not contact a BHGC, and 225 women who completed consult.

using patient self-report. The validation process was performed on 170 women who consented to be contacted for future research. Their ABHQ answers were reviewed and validated by BHGCs via a telephone call. Among the 170 women, the BHGC found that 47 women who triggered the USPSTF criteria had inappropriately answered the ABHQ. This validation revealed that 2 of the 9 USPSTF risk triggers were often inaccurately self-reported: (1) a first-degree relative with bilateral breast cancer; and (2) a first- or second-degree relative with breast and ovarian cancer. Because of these findings, women were not classified as being at elevated breast cancer risk if their only trigger was 1 of these 2 frequently inaccurate history elements.

Risk Assessment

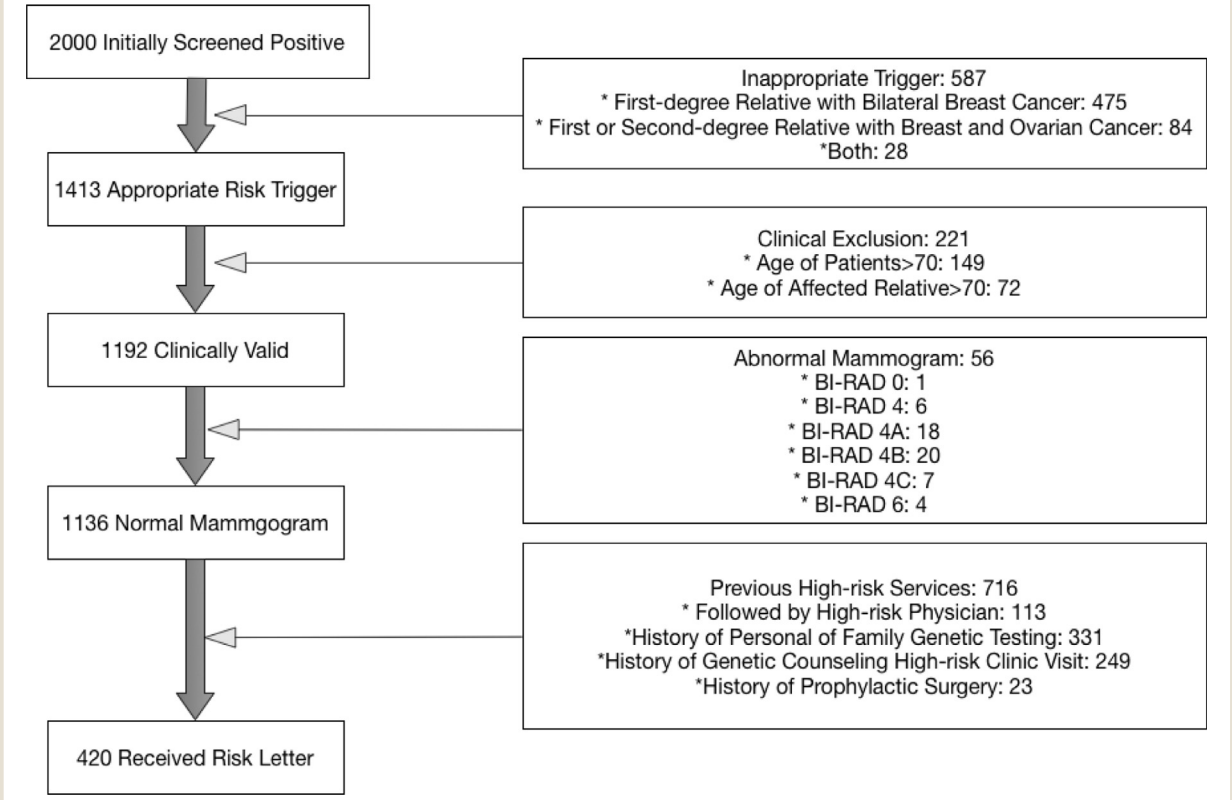
First, women were excluded from the study if they reported a breast cancer history on the ABHQ. Second, the ABHQ integrates 2 models to assess subjects' risk: (1) the USPSTF guidelines for genetics referral for Breast Cancer susceptibility gene 1 and 2 testing; and (2) the Gail model implemented via the Breast Cancer Risk Assessment Tool. A woman received an initial classification as high risk if she matched any of the family history criteria of the USPSTF guidelines (Table 1) or had a Gail model 5-year breast cancer risk score > 1.67 and was in the top 5% of scores within her age group. Putative high-risk subjects received a second-tier BHGC review of survey responses, medical records, and mammogram results. Subjects were excluded from the risk communication intervention if they had any of the following: (1) abnormal mammogram or ultrasound result (Breast Imaging Reporting and Data System 4-6); (2) previously evaluated as elevated breast cancer risk from genetic testing of appropriate family member, or previous visit with a genetic counselor, or previous consultation at the High Risk Breast Clinic, or previous risk-reducing prophylactic oophorectomies; (3) age older than 70 years, because women older than 70 years would automatically trigger the Gail model and likely not benefit from a high-risk intervention; or (4) breast cancer history in a relative whose age was > 70 years at the time of breast cancer diagnosis because the patient's hereditary breast cancer risk would be less affected by this relative.

The Breast Health Genetic Counselor Intervention

Women identified as high risk received a risk letter via mail. A similar letter was sent to their referring physician. A passive approach to patient contact was adopted at UCLA in that patients were asked to contact the BHGC to complete a telephone consultation. If after 2 weeks there was no response from the patient, the referring physician was sent a message through the EMR system and asked how to proceed among 3 follow-up options: (1) the BHGC could contact the subject on the physicians' behalf to complete the consultation (with a telephone call beginning with "I am calling on behalf of your primary care provider"); (2) the physician could follow-up with the patient and no further communication would come from the BHGC; or (3) the referring physician could decline any further follow-up on behalf of their patient.

During risk consultations, self-reported data were reviewed for accuracy and additional details about family members' cancer history (such as type of cancer, age of diagnosis, etc) were obtained.

Figure 2 Identification of Women at High Risk for Breast Cancer Eligible for Intervention Among a Population-Based Cohort



Abbreviation: BI-RAD = Breast Imaging Reporting and Data.

The BHGCs reassessed the patient's risk. After the review, some women's risk was downgraded by the BHGC. Women remaining at elevated risk were offered a consultation at the High Risk Breast Clinic. This clinic was described in detail to the patient via telephone, including the providers' availability for an appointment, the potential information to be discussed, length of visit, and pertinent insurance and logistical items. The BHGC consultation was documented in the EMR including any recommendations or referrals discussed.

The BHGCs used an average of 30 minutes for chart review for each subject and telephone call consultation duration ranged from 10 minutes to 30 minutes with an average of 20 minutes for high-risk women. No additional physical space was required because the BHGCs could use their own offices for chart review and consultation.

Statistical Analyses

We examined the characteristics of the first 2000 women who were initially identified as high risk for breast cancer from the ABHQ. We described the number of patients who met each exclusion criterion, the proportion of women who met each of the risk triggers, the number of patients who received risk letters and BHGC consultations, and the proportion who elected to pursue a referral to the High Risk Breast Clinic. We used χ^2 tests to examine the difference of the sociodemographic factors among subgroups.

Results

Risk Screening

Of 20,558 women who completed the screening survey, the first 2000 sequential women (9.7%) who were initially identified as being at elevated breast cancer risk were included in this analysis. This population had a mean age of 53.5 years (SD, 9.4), they were predominantly white or Asian, and approximately 1400 (70%) had a college degree (Table 1). Of these 2000 women, 587 (29%) were excluded after BHGC review for inappropriate triggers, 149 (7%) were excluded because of their age, 72 (4%) were excluded because of their affected relative's age, and 56 (3%) were excluded because of abnormal mammogram or ultrasound results. Of the remaining 1136, 716 (63%) were excluded because they had previously been identified as being at increased risk of breast cancer and had already been followed appropriately. This left a total of 420 women (21% of who were initially identified as high risk and 2% of the mammography screening cohort) who were sent risk letters (Figure 2).

Risk Triggers

Of the 420 women who were sent risk letters, 37 (9%) met age-specific Breast Cancer Risk Assessment Tool thresholds, 350 (83%) met the USPSTF family history guidelines (excluding the 2 inaccurately reported categories), and 33 (8%) met both (Table 2).

Table 2 Number of Subjects Identified as High Risk (n = 420) on the Basis of the Gail and the USPSTF Models

Trigger Breakdown: Receiving Letters	n
Gail Model	37
Gail and USPSTF	33
USPSTF	350
Two first-degree relatives with breast cancer, 1 < age 50	4
Three or more first- and second-degree relatives with breast cancer	50
History of male breast cancer	45
Jewish, 1 first-degree relative with breast or ovarian cancer	57
Jewish, 2 second-degree relatives with breast or ovarian cancer	15
Two or more first- and second-degree relatives with breast and ovarian cancer	123
Two or more first- and second-degree relatives with ovarian cancer	7
Multiple triggers	49

Abbreviation: USPSTF = US Preventive Service Task Force.

Uptake of BHGC Intervention

Of the 420 women who received risk information letters, 135 (32%) contacted the BHGC for a consultation. The remaining 285 (68%) did not respond so their physicians received a message through the EMR to help guide the next step. Women who contacted the BHGC, compared with women who did not contact the BHGC, were younger ($P < .001$) but these groups did not differ according to race or education level ($P = .46$ and .74, respectively). Among the 285 women who did not respond to the risk letter, the physicians of 23 women (8%) elected to personally contact their patients, 129 (45%) physicians did not respond to the inquiry, and 133 (47%) requested that the BHGC contact the patient on their behalf. Of the 133 patients who the BHGC tried to contact on the physician's behalf, 90 (68%) were successfully reached; 43 (32%) were not reachable. None of the 23 women contacted by their PCP reached out to the BHGC.

Final Triage

Overall, the BHGCs completed 225 risk consultations, accounting for 54% of the women at high risk for breast cancer who had not had this previously addressed. After the consultation, 63 (28%) were reclassified as nonelevated risk: 8 cases (13%) were erroneously labeled as high risk because of a technical error in the screening algorithm that was corrected early in the project; 54 (86%) were because of clarifications of the family history (eg, initially reported ovarian cancer in a relative but the true diagnosis was uterine or cervical cancer, reporting wrong relatives and counting great-aunts as aunts); and 1 (1%) because her family history was reportedly related to an environmental exposure (she was referred for follow-up with her PCP). Five women did not complete the consultations because they could not obtain or clarify the necessary family history. Three with a previous non-breast cancer diagnosis (2 with ovarian cancer and 1 with thyroid cancer) were referred to genetic counseling clinic. A total of 155 (69%) women who had a family history of breast and/or ovarian cancer were offered a consultation at the High Risk Breast Clinic. Among these, 107 (69%) expressed interest in this consultation and 51 (33%) completed it (Figure 3).

Table 1 shows the age, race, and education distributions among the subgroups of women who screened positive for breast cancer risk, a comparison of those in the initial cohort, those sent a risk letter, those who responded and did not respond to the risk letter, and those who completed a BHGC consultation. There was no significant difference among race or education among subgroups ($P = .97$ and .98, respectively). There was a significant difference of age among 4 groups, which was largely driven by the number of women who were older than 70 years old in the 2000-women cohort ($P < .001$).

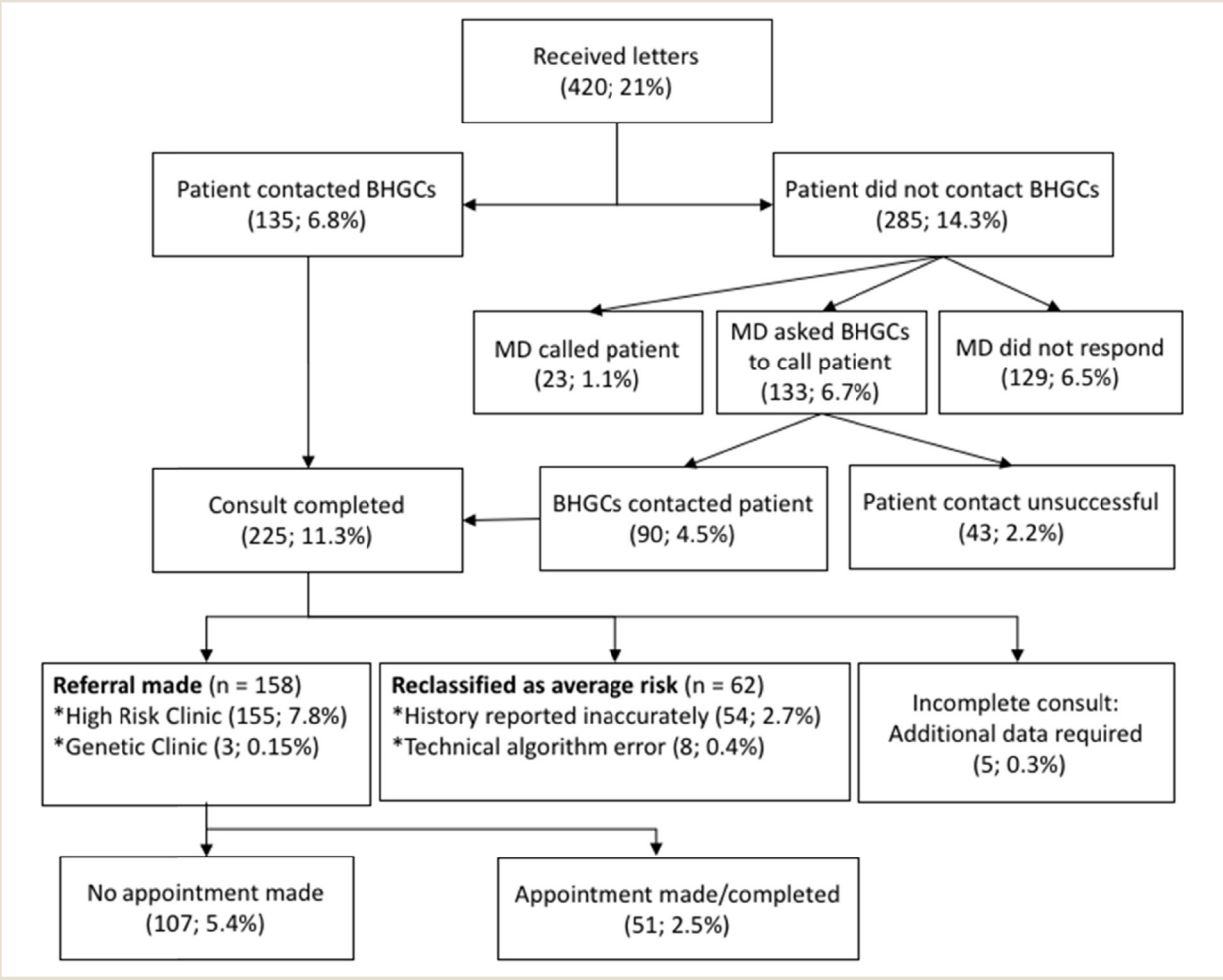
Discussion

In this study we analyzed the implementation of a population-based breast cancer risk assessment program with the goal of identifying women at high risk of breast cancer and providing early intervention. Although this program helped 51 women to receive a high risk clinic appointment, they represented a small subset of the 225 women who received BHGC consultation, the 420 women who received a risk communication, the 2000 women who automatically triggered a high-risk threshold, and the total population of 20,558 who went through screening. We suggest that this process cannot be fully automated without significant risk of communicating risk on the basis of inaccurate patient self-report. Such a program requires significant human resources. This study highlights the operational challenges and considerable resources required for a population-based, semiautomated approach to breast cancer risk assessment and communication.

Two previous studies implemented a risk assessment program to identify women at a higher risk of breast cancer. The Owens et al[25] "Ready, Set, Go Gail project" was designed to use the Gail model to identify high-risk women, and the risk information was sent to patients' primary care physicians who were to provide risk consultation and refer patients to a comprehensive breast care center. The project identified 15.2% women as high risk using the Gail model. The Shah et al[26] "Beaumont hospital experience" was designed to use a modified Gail model as well as patient history and previous radiation therapy to identify women at high risk of breast cancer. In total, 30% of women were identified as high risk with 17% identified using the Gail model and 13% who were identified using additional personal and family information. The present study showed 874 (4.3% including those newly identified and those previously having received attention) as high risk.

One difference between our study and previous studies is the risk model used; we used a dual risk stratification mechanism with (1) a 5-year Gail model risk > 1.67, and having a risk in the top 5% of the age-matched cohort; and (2) the USPSTF guideline was embedded in our screen criteria. We identified 2000 (10%) high-risk women from the initial automated mechanism. Another difference between our work and previous studies was that we validated the accuracy of the risk information. Among those initially identified as high risk, 587 (29%) were reclassified as non–high-risk after the information validation process. After BHGCs manually checked each patient's risk information, only 420 (2%) of the screened population met criteria to receive risk feedback.

Figure 3 Uptake of the Breast Health Genetic Counselor (BHGC) Intervention



Ideally, family history collection strikes a balance between an easily administered tool that minimizes patient burden and sufficiently detailed information collection for an automatic preliminary risk assessment. Although an automated approach is desirable when screening a large number of women while attempting to collect a relatively extensive family history, in this project the automated screening proved fallible and manual attention was needed to clarify family history in many instances.

Our project revealed several areas of caution in developing a program to identify women at risk for breast cancer. For example, 149 (7%) women older than 70 years could be excluded automatically instead of through manual verification by BHGCs. Similarly, questions could be modified to ask about the age of relatives who developed cancer. However, family history questions are often complex and women often do not know the answers or are misinformed. Although most women in our study had a college degree, 587 (29%) women who triggered USPSTF criteria provided responses that were later revised after BHGC review. Our data also show that 716 (36%) women identified as high risk for breast cancer had already received a risk evaluation. This is good news and suggests that primary care doctors and specialists are attending to this issue for many of their patients. It should be noted that this screening was conducted in a population of highly educated women with access to high-quality primary care. In populations of patients with less recognition of breast cancer risk, a larger proportion of screened women would be expected to receive referrals to the high risk clinic.

A unique feature of our work is that the BHGCs, who were familiar with all risk reduction options and services offered by the high risk clinic, consulted directly with the high-risk women. Using breast cancer risk reduction therapies such as tamoxifen, raloxifene, or aromatase inhibitors to reduce risk of invasive breast cancer of high-risk women is supported by USPSTF,[27] American Society of Clinical Oncology,[28] and National Comprehensive Cancer Network (NCCN)[29] guidelines. However, barriers exist to using these therapies. Barriers include unavailability of an easily accessible and accurate prediction tool,[30] primary care physicians having insufficient education about risk reduction options and lacking training in risk assessment counseling, and time limitations.[31,32] Shah et al and Owen et al[25,26] reported that primary care physicians were not comfortable with the risk consultation. For only 15% of high-risk women were referrals made, only 7% went to the

consultation clinic, and only 2% of women took risk reduction medication when the consultation was conducted by their primary care physician,[25] whereas the risk reduction medication uptake rate was 54% if a comprehensive risk assessment and consultation were provided.[33] In our study, BHGCs ultimately referred 38% of high-risk women to the high risk clinic and 12% made a high risk clinic appointment.

Although the process we describe is resource-intensive, we show that it is feasible. A next step would be to evaluate the effectiveness of implementing such a risk assessment program, which aims not only to identify high-risk women but also to communicate with them and make effective referrals. Our experience suggests that a manual review process is needed to ensure that the "right" women are referred to the "right" treatment. Outcomes to be measured would include clinical and economic effects on screened women as effected through risk reduction and modified screening protocols.

Another unique point of this program was that we used a 2-step approach to contact patients. The passive approach (sending a letter with information and instructions on how to contact the breast cancer risk assessment specialist) resulted in a proactive contact from patients who were interested and willing to participate in a breast cancer risk assessment and takes little in the way of time or resources. We found that among women who were older than 60 years, only 2 women contacted BHGCs and 63 did not. Therefore, alternative strategies of connecting older women and BHGCs are warranted. However, incorporating primary care physicians allowed for a more tailored approach for patients who did not respond to their initial letter. There was a high consultation rate (67%) for patients contacted by the BHGCs on behalf of the referring physician. This suggests the importance of incorporating the referring physician in a risk screening program.

There are several limitations in our study. We found that the most common reason for revising the initial high-risk assessment is that 2 of our high-risk triggers proved to be consistently inaccurately reported: (1) having a relative with bilateral breast cancer; and (2) having a relative with breast and ovarian cancer. Because of the Athena study design, we were not able to remove these 2 questions from the ABHQ in the middle of the study, so we had to manually exclude women who qualified exclusively because of these triggers. Second, using USPSTF guideline and the Gail model for risk assessment might limit the number of women identified as high risk; using the NCCN guideline for risk assessment would likely identify more at-risk patients. Furthermore, we did not include women with a history of breast cancer, although this is an important group of women, because they likely receive genetic testing and risk reduction counseling from cancer specialists and other mechanisms. Third, there was a low response rate from the contacted physicians. Fourth, we noted that the population in this study was well educated and with good access to medical care; our findings might not reflect other patient populations.

Conclusion

In summary, implementing a semiautomated screening mechanism to collect personal and family history information to identify women at high risk of breast cancer is feasible, but manual efforts are needed. Our recommendations for the planning and development of a population-based breast cancer risk assessment program include examining the use of additional risk factors, newly discovered genetic variants, or validated risk models beyond the Gail model or USPSTF, and developing additional methods to improve the accuracy of patient-reported breast cancer risk factors, particularly methods to more accurately collect information on the cancer diagnoses of family members.

Clinical Practice Points

- The tools exist to implement population-based screening to identify women at high risk of breast cancer, but few programs have been tested.
- We implemented a population-based breast cancer risk assessment program that included validation of patient-reported information and exclusion of patients who had already received attention to breast cancer risk.
- Automated risk assessment for breast cancer is inadequate and patient-reported information requires review.
- Population-based risk assessment must account for women who are already aware of their increased risk and have received services to reduce risk.
- Population-based breast cancer risk screening is feasible but resource-intensive. Future implementations could incorporate genetic testing and should evaluate clinical and utilization outcomes.

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Disclosure

The authors have stated that they have no conflicts of interest.

Supplemental Data

Supplemental figure accompanying this article can be found in the online version at https://doi.org/10.1016/j.clbc.2019.02.009.

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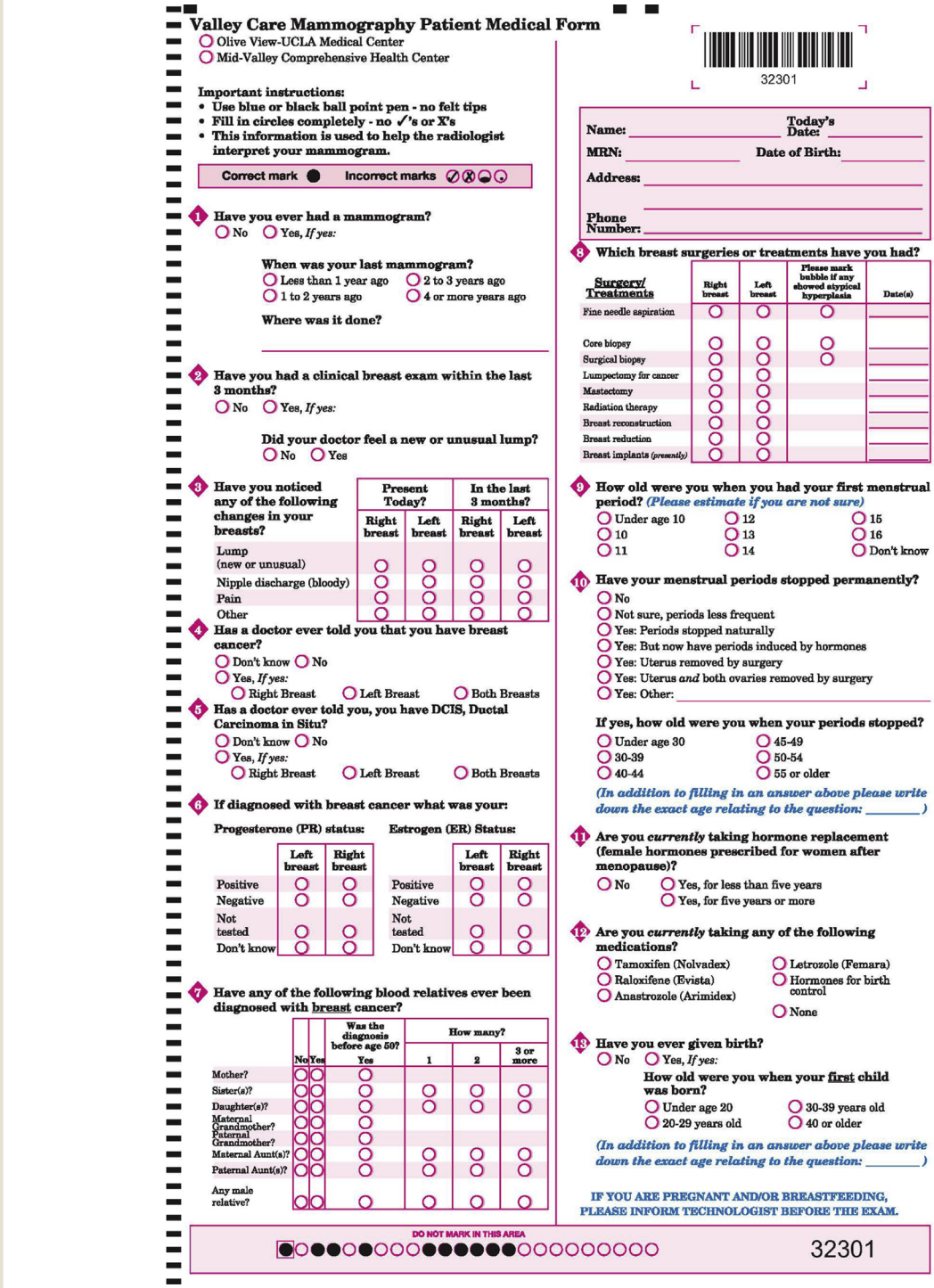
Supplemental Data

Supplemental Figure 1 Personal History and Family History Collection Form



Valley Care Mammography Patient Medical Form

- ○ Olive View-UCLA Medical Center
- ○ Mid-Valley Comprehensive Health Center

32301

Important instructions:
- Use blue or black ball point pen - no felt tips
- Fill in circles completely - no ✓'s or X's
- This information is used to help the radiologist interpret your mammogram.

Correct mark ● Incorrect marks ⊘ ⊗ ◒ ⊙

Name: _____ Today's Date: _____

MRN: _____ Date of Birth: _____

Address: _____

Phone Number: _____

1 Have you ever had a mammogram?
○ No ○ Yes, *If yes:*

When was your last mammogram?
○ Less than 1 year ago ○ 2 to 3 years ago
○ 1 to 2 years ago ○ 4 or more years ago

Where was it done? _____

2 Have you had a clinical breast exam within the last 3 months?
○ No ○ Yes, *If yes:*

Did your doctor feel a new or unusual lump?
○ No ○ Yes

3 Have you noticed any of the following changes in your breasts?

	Present Today?		In the last 3 months?	
	Right breast	Left breast	Right breast	Left breast
Lump (new or unusual)	○	○	○	○
Nipple discharge (bloody)	○	○	○	○
Pain	○	○	○	○
Other	○	○	○	○

4 Has a doctor ever told you that you have breast cancer?
○ Don't know ○ No
○ Yes, *If yes:*
○ Right Breast ○ Left Breast ○ Both Breasts

5 Has a doctor ever told you, you have DCIS, Ductal Carcinoma in Situ?
○ Don't know ○ No
○ Yes, *If yes:*
○ Right Breast ○ Left Breast ○ Both Breasts

6 If diagnosed with breast cancer what was your:

Progesterone (PR) status:

	Left breast	Right breast
Positive	○	○
Negative	○	○
Not tested	○	○
Don't know	○	○

Estrogen (ER) Status:

	Left breast	Right breast
Positive	○	○
Negative	○	○
Not tested	○	○
Don't know	○	○

7 Have any of the following blood relatives ever been diagnosed with breast cancer?

	No	Yes	Was the diagnosis before age 50? Yes	How many? 1	2	3 or more
Mother?	○	○	○			
Sister(s)?	○	○	○	○	○	○
Daughter(s)?	○	○	○	○	○	○
Maternal Grandmother?	○	○	○			
Paternal Grandmother?	○	○	○			
Maternal Aunt(s)?	○	○	○	○	○	○
Paternal Aunt(s)?	○	○	○	○	○	○
Any male relative?	○	○	○	○	○	○

8 Which breast surgeries or treatments have you had?

Surgery/ Treatments	Right breast	Left breast	Please mark bubble if any showed atypical hyperplasia	Date(s)
Fine needle aspiration	○	○	○	
Core biopsy	○	○	○	
Surgical biopsy	○	○	○	
Lumpectomy for cancer	○	○		
Mastectomy	○	○		
Radiation therapy	○	○		
Breast reconstruction	○	○		
Breast reduction	○	○		
Breast implants *(presently)*	○	○		

9 How old were you when you had your first menstrual period? *(Please estimate if you are not sure)*
○ Under age 10 ○ 12 ○ 15
○ 10 ○ 13 ○ 16
○ 11 ○ 14 ○ Don't know

10 Have your menstrual periods stopped permanently?
○ No
○ Not sure, periods less frequent
○ Yes: Periods stopped naturally
○ Yes: But now have periods induced by hormones
○ Yes: Uterus removed by surgery
○ Yes: Uterus *and* both ovaries removed by surgery
○ Yes: Other: _____

If yes, how old were you when your periods stopped?
○ Under age 30 ○ 45-49
○ 30-39 ○ 50-54
○ 40-44 ○ 55 or older

(In addition to filling in an answer above please write down the exact age relating to the question: _____)

11 Are you *currently* taking hormone replacement (female hormones prescribed for women after menopause)?
○ No ○ Yes, for less than five years
○ Yes, for five years or more

12 Are you *currently* taking any of the following medications?
○ Tamoxifen (Nolvadex) ○ Letrozole (Femara)
○ Raloxifene (Evista) ○ Hormones for birth control
○ Anastrozole (Arimidex) ○ None

13 Have you ever given birth?
○ No ○ Yes, *If yes:*

How old were you when your first child was born?
○ Under age 20 ○ 30-39 years old
○ 20-29 years old ○ 40 or older

(In addition to filling in an answer above please write down the exact age relating to the question: _____)

IF YOU ARE PREGNANT AND/OR BREASTFEEDING, PLEASE INFORM TECHNOLOGIST BEFORE THE EXAM.

DO NOT MARK IN THIS AREA

32301

Supplemental Figure 1 (Continued)

14 Have any of the following blood relatives ever been diagnosed with ovarian cancer?

	No	Yes	Was the diagnosis before age 50? Yes	How many? 1	2	3 or more
Mother?	○	○	○			
Sister(s)?	○	○	○	○	○	○
Daughter(s)?	○	○	○	○	○	○
Maternal Grandmother?	○	○	○			
Paternal Grandmother?	○	○	○			
Maternal Aunt(s)?	○	○	○	○	○	○
Paternal Aunt(s)?	○	○	○	○	○	○

15 Have any of your relatives ever been diagnosed with bilateral breast cancer (cancer in both breasts)?
○ Yes ○ No ○ Don't know

16 Have any women in your family ever been diagnosed with both breast and ovarian cancers?
○ Yes ○ No ○ Don't know

17 Have you ever had a hysterectomy (a surgery to remove your uterus or womb)?
○ Yes ○ No ○ Don't know

18 At what age did you have your hysterectomy?
○ Before age 25 ○ 50-54
○ 25-34 ○ 55-59
○ 35-44 ○ 60-64
○ 45-49 ○ 65 or over
(In addition to filling in an answer above please write down the exact age relating to the question: _____)

19 Have you ever had one, both, or part of an ovary removed?
○ No
○ Yes - both ovaries were removed at the same time
○ Yes - only one ovary was removed
○ Yes - only part of one ovary was removed
○ Yes - but I don't know whether one or both ovaries were removed
○ Don't know

20 If you marked yes to the previous question, at what age did you have your ovary or ovaries removed?
○ Before age 25 ○ 50-54
○ 25-34 ○ 55-59
○ 35-44 ○ 60-64
○ 45-49 ○ 65 or over
(In addition to filling in an answer above please write down the exact age relating to the question: _____)

21 Have you or any of your relatives ever had genetic testing for breast cancer risk?
○ Yes ○ No ○ Don't know

22 Do you currently have any limitations in your regular activities?
○ None ○ A little bit ○ A lot

23 Have you ever been diagnosed or treated for any of the following health issues?
(mark all that apply)
○ Alzheimer's disease, dementia
○ Anemia or other blood disease
○ Back pain
○ Being Overweight (Obesity)
○ Cancer (other than Breast Cancer or Skin Cancer)
○ Chronic Obstructive Pulmonary Disease
○ Congestive Heart Failure
○ Depression
○ Diabetes (problem with your blood sugar levels)
○ Heart Attack
○ Heart Disease
○ High Blood Pressure
○ Kidney Disease
○ Liver Disease
○ Lung Disease (e.g., asthma, pulmonary fibrosis, etc.)
○ Osteoarthritis, degenerative arthritis
○ Rheumatoid arthritis
○ Stroke
○ Thyroid Disease
○ Ulcer or Stomach Disease
○ Don't know
○ None
○ Other conditions (not listed)

24 If yes, do these conditions cause limitations and interfere with your regular activities?
○ Not at all ○ Moderately ○ Extremely
○ Slightly ○ Quite a bit

25 Considering your health over the last month, would you say your health is?
○ Excellent ○ Good ○ Poor
○ Very good ○ Fair

26 How often do you have a drink containing alcohol?
○ Never ○ 2-3x/week
○ 1x/month or less ○ 4 or more x/week
○ 2-4x/month

27 On a typical day that you have alcohol, how many drinks do you have?
○ 1 or 2 ○ 3 or 4 ○ 5 or 6 ○ 7 or 9 ○ 10 or more

28 What best describes your current marital status?
○ Married ○ Never married
○ Widowed ○ Divorced
○ Living with a partner in a marriage-like relationship ○ Separated

29 How tall are you in feet and inches? Feet: 3 4 5 6 7 — Inches: 0 1 2 3 4 5 6 7 8 9 10 11
How much do you weigh in pounds? Pounds: 0 1 2 3 4 5 6 7 8 9

30 Racial or ethnic background?
(fill in all that apply)
○ African-American/Black ○ Japanese
○ Caucasian/White ○ Filipina
○ Hispanic/Latina ○ Vietnamese
○ American Indian ○ Other Asian
○ Chinese ○ Other, non-Asian

31 How many years of schooling have you had?
○ Some high school or less
○ High school graduate
○ Some college or technical school
○ College graduate or more

32 Do you have any Ashkenazi (Eastern European) Jewish ancestry in your family?
○ Yes- only on my father's side ○ Yes- not sure what side of the family
○ Yes- only on my mother's side ○ No ○ Don't know
○ Yes- on both sides

The Athena Breast Health Network is a statewide collaboration to improve care for breast cancer patients by designing and testing system-wide new approaches to research, technology, and health care delivery. The goal of the Athena research is to provide personalized health care and advance the science of prevention, screening, diagnosis, and treatment of breast cancer.

1. **I give my permission to be contacted in the future by research staff.** *(This will give you the opportunity to participate in breast cancer related studies)*
○ Yes ○ No

2. **I am interested in giving a small sample saliva at the end of my visit today for future research purposes.** *(If yes, you will be given a separate consent to sign for this)*
○ Yes ○ No

For questions: please call Athena-UCLA line: 310-206-5121.
Athena-Olive View contact: (818) 364-3308

IF YOU ARE PREGNANT AND/OR BREASTFEEDING, PLEASE INFORM TECHNOLOGIST BEFORE THE EXAM.

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